STANFORD UNIVERSITY MEDICAL CENTER
STANFORD, CALIFORNIA 94305 • (415) 321-1200

STANFORD UNIVERSITY SCHOOL OF MEDICINE
Department of Genetics

January 22, 1973

Honorable Birch Bayh
United States Senate
Washington, D.C. 20510

Dear Senator Bayh,

I am pleased to note your interest in research on genetic disease as indicated in your letter of January 11.

It would be a mistake to formulate a comprehensive attack on genetic disease in the same context of a well defined mission that we think of in relation to efforts like nuclear energy and the space program. Our principal requirements for advances in genetics are basic new knowledge although much more certainly could be done to develop the practical utility of what we already know. However, we are going through a period where it is becoming increasingly difficult to obtain broad base support for basic research without encapsulating it in a definite targeted mission and, pragmatically speaking, this may now be the only way that further progress can be achieved.

I have been pleased to see a number of measures which have received legislative support leading to special programs for diseases like sickle cell anemia and Cooley's anemia. These are entirely laudable; but they hardly represent the ideal approach to responding to a wide ranging set of problems whose basic elements know no ethnic boundaries. I would therefore strongly favor a reorganization of such programs so that they would achieve a proper but well ordered place in a comprehensive attack on genetic disease, along the lines of the testimony that I gave to the House Appropriations Committee a couple of years ago. Their response was a brilliant start and I believe the time may now be ripe to take some further steps, the most dramatic of which might perhaps be the redesignation of the National Institute of General Medical Sciences into the National Institute of Genetics and Other Medical Sciences. This has the advantage of ensuring that a particular institute has a well-defined mission in the field of genetic disease; one may have to guard against the possible hazard that other institutes -- like Heart and Lung, Allergy, Metabolic Disease, and others may slacken the important efforts they are also making in genetic diseases that cut across their own categorical mission.

At the present time I would have to say that our most serious problem is not in the table of organization of research efforts but in the overall funding of health related research. This has reached crisis dimensions in the last few weeks with the announcements of intended severe cutbacks in already authorized programs of the NIH and in particular with the avowed expectation that research training grants, including those that have played an important part in providing skilled professionals for

over

genetic research are to be abolished. I have no hesitation in saying that the withdrawal of this kind of support would be catastrophic for this department of genetics which was founded here in 1959 explicitly with this kind of financial help. The threatened withdrawal of the training grant program will remove the only basis that we can now foresee for the recruitment and support of graduate students and postdoctoral fellows in genetics. It also provides a significant proportion of the salary base for our faculty who, of course, have spent a significant part of their time in these graduate educational activities, as well as in the promulgation of modern genetic concepts to our medical students and house-officers. In other times the problem might have been one of merely shifting the nominal category of support from research training to research production but I do not have to tell you the pressure that is also applied against any hope of expansion in that direction. Cutbacks in support from other agencies and for other research programs have already necessitated a shrinkage in our research staff and we are in a desperate struggle to prevent further erosion of a capability that has been built up painfully and expensively over the years.

I would then view recommendations for administrative reorganization as having their most urgent role the cultivation of informed interest in and debate about the merits of such general research support; I am prepared to respond to <u>any</u> framework that would allow the survival of our programs as a necessary precondition to new arrangements that might improve the coordination of existing efforts and the establishment of realistic goals for human betterment. I hope this candid statement of where our problem really lies will encourage you to make even stronger efforts in spite of the deterrence that you indicate you expect from the administration.

These remarks have possibly already answered some of your other specific questions. The National Institute of Health is certainly the appropriate agency for expanded research efforts in genetics. You inquire about the possible effectiveness of "a grant program encouraging private research" in contrast to "federal research". I assume that this postulates the indespensability of federal financial support for there is simply no way in which private philanthropy or profit-oriented free enterpise can assume the necessary responsibility. It is, of course, important that we maintain a pluralistic approach and private foundations can certainly play a role out of proportion to their meager financial capability by finding accidental or structural gaps in government-based programs. Free enterprise, especially the drug industry, allows the market economy to play an important role in resource allocation which is especially apt for product development (contra basic research) of drugs and devices. For technical reasons these play a secondary role in the area of genetic disease and we face a constant moral difficulty in attempting to rely on the expectation of profit from the need for life-saving intervention as the technique of guiding investment in very long-range, deferred pay-off types of programs.

There are a few important efforts that would be a good match to the special capabilities of "federal research" efforts like those that might involve some of the national laboratories that were originally established to meet needs in the field of atomic energy and space. The large-scale screening of chemical environmental additives for genetic hazard and the establishment of centers for the routine analysis of complex protein structures would be examples of important and well-defined programs that

over

might well utilize national laboratory capabilities. Another is the development of sophisticated electronics for the mechanized diagnosis of chromosome patterns. However, the larger part of research efforts in this field, as in other health research fields, would be better aportioned to the pluralistic genius of workers at academic institutions throughout the country and in definite measure also at the NIH campus itself in Bethesda.

You will hear vicious propaganda that we should stop producing highly skilled manpower at Ph.D. levels because there is a shortage of jobs for these people to occupy. We have had some difficulty in finding ideal positions for some of our graduates but they have all been well placed in highly productive situations. The job shortage is an artificial one which results from the turnaround in federal policy with respect to the support of research. To use this as the argument for continued cutbacks in support of the combined research and training process is, of course, to insist on the realization of a self-fulfilling prophecy. If the country wants to have the benefit of continued advances in medical science it is obligatory that there be a continued investment which still remains a very small percentage of total "sales" in the health field that, for reasons already explained, can only come from federal sources. If we were really to go to a free enterprise economy to adjust manpower allocation in this field you would have to contemplate changing our patent laws to permit scientists to profit in full measure from their basic scientific discoveries in the same fashion as inventors are rewarded for their ultimate practical application. And you would also have to promise not to engage in recriminations about holding up the sick and the dying for all that the traffic could bear. I do not believe that any thoughful person would recommend such a redirection of human policy.

Sincerely yours,

Joshua Lederberg
Professor of Genetics

JL/rr